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GUIDELINES ON COUNSELING OF HIV INFECTION AND AIDS

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**GUIDELINES ON COUNSELING
OF
HIV INFECTION AND AIDS**

AIDS/STDs Section
Ministry of Health Malaysia
KUALA LUMPUR

PREFACE

This guide has been developed by staff of the Ministry of Health Malaysia on the basis of recommendations and meetings held by the various experts in this country. Psychiatrists from around the country have provided substantial input, and special mention needs to be addressed to Yang Berbahagia Dato' (Dr) Hj Abdul Aziz bin Abdullah, Dr. Safraz Manzoor Hussain and Dr. Ahmad Rasidi bin Saring.

This guide is intended for those who provide counselling to those who are infected or affected by the HIV Infection. It is hoped that its reference will be useful a tool as to promote consistency in the field of counseling on HIV Infection for the Malaysian public.

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INTRODUCTION

Human Immunodeficiency Virus Infection and Acquired Human Immunodeficiency Syndrome (AIDS) is caused by a virus called the Human Immunodeficiency Virus (HIV) which was isolated in 1983. Entry of virus into the human body leads to its spread to all tissues in the body. The virus has a predilection for the cells of the immune system that forms the body's natural protection against infection. This leads to a depletion of the body's natural resistance and a state of immunodeficiency. The body becomes more prone to infection by opportunistic organisms which can lead to death.

The progression from the time of entry of the virus to death takes varying duration. From studies it has been found that 1.0% of HIV positive patients progressed to AIDS within two years, 12.0% within 5 years, 53.0% within 10 years and 61.0% within 12 years. During this time the individual may be well for long periods but remains infective for life.

HIV infection and AIDS is an incurable disease or condition at the present time. There is no effective treatment or vaccine till today. This is further aggravated by the tremendous psychosocial impact on the person with HIV infection and AIDS, the family and community. However, it must be emphasised that AIDS and HIV Infection is a preventable condition, mainly related to the lifestyle and behaviour of an individual. Therefore, counselling plays a crucial role in the prevention, transmission and management of HIV infection and AIDS and allows the individual to make informed decisions that can improve lifestyles.

1.1 Epidemiology

Cases of AIDS were first reported in the United States in 1981. Since then, it has become a worldwide pandemic. Until 1993, World Health Organization (WHO) has estimated over 2.5 million

cases of AIDS among adult and 30 million carriers worldwide. It is also estimated there are half a million cases of AIDS and over one million HIV carriers in children.

In Malaysia the first AIDS case was reported in 1986. Up to November 1994, 117 cases of AIDS have been diagnosed with 81 deaths. Up to the same period, there were 10,621 HIV carriers reported. It is projected that by 1995, there will be 32,000 carriers and 2,500 cases of AIDS.

The vast majority of carriers reported are among the intravenous drug abusers (IVDUs) ie 95.0% and males form 96.5%, of these carriers. Females form 13.0% and males 87.0% of the AIDS cases. It is important to emphasise that there may be many more undetected carriers in the population.

1.2 Mode of Transmission

There are three main modes of transmission of HIV viz sexual, parenteral and perinatal. It has been reported that the virus is found with higher concentration in blood, semen, cervical, vaginal and anal secretions. However, it is also found in other body fluids.

(a) Sexual transmission

Sexual transmission is the most frequent mode of transmission globally. An infected person can spread the virus to his or her sexual partner/s through unprotected, penetrative heterosexual or homosexual intercourse.

(b) Parenteral transmission

This occurs through the transfusion of infected blood or blood products. Commonly in Malaysia, this mode of transmission occurs among drug abusers who share needles.

(c) Perinatal transmission

This occurs from an HIV infected mother during pregnancy or at time of delivery. The risk of transmission of the infected mother to the foetus is about 20.0% - 40.0%.

1.3 Definition and Clinical Classification of HIV Infection and AIDS

HIV infection is defined as the stage when an individual is infected by HIV, indicated by the presence of anti-HIV antibody and/or HIV P24 antigen in the serum confirmed by a designated Reference Laboratory.

AIDS is defined as when an individual has the anti-HIV antibody confirmed to be positive as above and in addition has at least one of the AIDS defining conditions and CD4 T-cells lymphocyte count of less than 200/ml.

In counselling and management, it is very important that this distinction is recognised. The clinical classification of HIV infection and AIDS is as follows :

Group 1: Acute Seroconversion State

From the time of entry of the virus until production of antibodies starts. This generally takes 2 to 12 weeks. The point of seroconversion is manifested by non-specific symptoms of fever, night sweats, skin rash, headache and cough.

Group 2: Asymptomatic HIV Infection

The HIV carrier enters into an asymptomatic period and remains healthy. This stage lasts from a few to several years.

Group 3: Stage of Persistent Generalised Lymphadenopathy (PGL)

Group 4: AIDS

Due to the state of immunodeficiency and fall in CD4 cell count, opportunistic infections and special types of cancers can occur. The person becomes weak, lose weight and is rather ill. This stage is further subdivided on the basis of CD4 cell counts.

1.4 Testing for HIV

Laboratory test for the presence of HIV infection in the body is done by a two-stage process.

(a) Screening Test

This is done in most Government Hospitals and private laboratories by use of

ELISA technique and result is usually available within two days or less. If positive

(reactive), it is then necessary to confirm by other supplementary tests.

(b) Supplementary Tests

These are done at Institute Medical Research (IMR) by Line Immunoassay (LIA) or Western-Blot which can detect the presence of both HIV I and HIV II virus. Only when a supplementary test is reactive it is confirmed positive. Other tests which are more sophisticated are also available at IMR for purpose of monitoring response to treatment or detection of HIV antigen in young babies below three months old.

CHAPTER 2

2.1 What is HIV / AIDS Counselling?

HIV and AIDS counselling is an active process of communication and dialogue between a trained counsellor and the client who presents with problems related to HIV or AIDS and in a view to assist the client to deal with these problems adequately and appropriately.

2.2 Objectives of HIV / AIDS Counselling

HIV \ AIDS counselling is done to achieve various objectives. Among them are :

- a. Prevention of infection through promotion of healthy life styles, behaviour, moral and spiritual values.
- b. Prevention of transmission through modification of risky lifestyles and behaviours.
- c. Provision of psychosocial support to those infected and /or affected by HIV / AIDS to achieve optimum level of functioning and satisfactory quality of life.
- d. To complement health education and correct misconceptions or myths about HIV and AIDS.

2.3 Who Needs Counselling

There are individuals or groups that require counselling. Among them are :

- a. those who practise risky behaviours and lifestyles such as individuals with multiple sexual partners, drug abusers who share needles, prostitutes etc.
- b. partners of the above groups of people.

- c. those who request testing to be done for reasons best known to them. This includes the "worried well".
- d. those who are referred for counselling by other caregivers.
- e. those who been tested for HIV found to be negative or positive.
- f. those with presenting medical or neuropsychiatric symptoms suggestive of AIDS.
- g. those with psychological and other psychosocial problems related to HIV / AIDS such as depression, rejection etc.
- h. significant others related to care and management of HIV infected person.
- i. caregivers involved in the management of cases with presenting problems of their own related to the care of their clients.

2.4 Who is HIV/AIDS Counsellor ?

For a person to become a good and effective counsellor, one must be trained in skills and technique of counselling, has adequate knowledge in issues of HIV infection and AIDS and involved in management of these cases eg. health care workers including Doctors, nurses etc; Drug Rehabilitation Officers; Prison Officers; Non-Governmental Organization (NGOs) workers; religious personnel and community leaders.

2.5 What are the Fundamentals of Counselling ?

The counsellor should have an attitude that is responsible and caring in his/her management of his/her clients and willing to accept his/her clients in a non-judgemental manner with regards to their sexual practices and habits, sub-cultural groups such as prostitutes, transvestites, drug dependents etc.

The issue of confidentiality is often mentioned in counselling. This must be strictly observed as far as possible within the counselling setting which may include the co-counsellors or

assistants. The client has to be informed of requirement of legal notification in cases of positive results.

The setting should be done in privacy, not in open wards to ensure smooth progression of the process of counselling. In counselling, time is an important factor. The counsellor must ensure adequate time is given and punctuality must be strictly observed at almost all times. There may be occasion that a client may request unscheduled appointments to which the counsellor has to deal with.

2.6 Technique of Counselling

The effectiveness of counselling depends on the techniques used by the counsellor and in the initial phase, rapport must be established. This may be achieved by self introduction, hand shake and ensuring sitting arrangements must be such to minimize obstacles and encourage eye contact in a non-confrontational posture. The counsellor should speak in a non-threatening tone or manner. It is also important to emphasise that the counsellor should be able to empathise with the client. In interviewing clients, skills must be applied to use open-ended questions and not one-word response. The counsellor must be very tactful to guide the interview should the client digress. Questions asked to the clients should be ranked and if clients have several concerns they should also be ranked. Avoid use of technical terms and if certain jargon terms are used by the clients, they should be clarified.

It is also important for the counsellor to be able to evaluate the emotional state and explore the feelings of the client such as worries, anxieties, mood, fears, suicidal ideas, hope for the future etc. The counsellor should allow ventilation of various feelings such as fear, anger, despair etc.

It is also important that the counsellor be honest in providing all information while giving support and must avoid giving false reassurances to the clients while on the other hand giving hope to them.

CHAPTER 3

ISSUES IN HIV / AIDS COUNSELLING

In counselling there are several issues which are encountered which could be categorised as :

- (a) General Issues
- (b) Social Issues
- (c) Sex and Drug Related Culture Sensitive Issues
- (d) Psychological Issues

It is very important for the counsellor to be able to address the above issues.

In general issues, lay beliefs and misconceptions have to be corrected, for example virus can be transmitted through toilet seats, sharing of common utensils; transmission does not occur through casual contact such as hand shake etc. It is a common misconception among the public that asymptomatic carrier and AIDS are considered the same category; all drug addicts have AIDS and infected person cannot have sexual intercourse. The counsellor has to deal with these issues and correct the misconceptions.

The common social issues that the counsellor has to deal are marriage, divorce, employment and financial problems.

Often, the counsellor has got to deal with sensitive issues dealing with sexual and drug practices related to HIV and AIDS. Careful enquiry and skill in interview has to be done by the counsellor so as not to offend the client and maintain good rapport. For example there are times detailed interview has to be done on masturbation and other sexual practices; use of condom, sexually transmitted disease etc. The counsellor may have to explain the purpose of the enquiry.

In the issue of safer sex, it has to be mentioned that use of condom decreases the risk of transmission. There are instances when the counsellor has to instruct the right technique of using condom. In this sex and drug related culture sensitive issues, it must be emphasized that the objective is to prevent the spread of transmission through modification of lifestyles and behaviours.

In handling psychological issues of various forms eg. denial, shock, fear, anxiety, depression and guilt, suicidal ideas and threat, the counsellor must be able to recognize the symptoms and severity and deal with them accordingly.

In certain instances, the counsellor may feel the need to refer the client to a Psychiatrist, for instance when the clients present with signs of cognitive impairments, psychotic symptom/s, severe depression and suicidal thoughts for further opinion and management.

CHAPTER 4

STAGES OF COUNSELLING

4.1 Pre-test Counselling

Since AIDS and HIV infection are associated with profound psychosocial impact to the individual, family and community, pre-test counselling should always be done by a counsellor. It is also recommended that the pre-test counselling is done even in cases of mandatory testing; for example in the prison and drug rehabilitation centers. Exemption for pre-test counselling could be considered in a cognitively impaired person, dementing illness, psychotic patients and mental retardation who are suspected on clinical grounds to be infected.

The objectives of pre-test counselling are :

- a. *To assess reasons for test to be done*
- b. *To evaluate knowledge of the client in issues concerning HIV infection and AIDS, eg. "window period", risk behaviours, mode of spread etc.*
- c. *Assessment of risk behaviours including the last possible exposure to the virus.*
- d. *Evaluation of various psychological reactions in view to prepare patient for the outcome of the test.*

This should also cover discussion in the procedures of the test, how result to be given, implication of test results and plan while waiting for the result such as discussion with spouse, informing family members etc.

It is important to note that the decision whether the test to be done or otherwise is very much the decision of the client for voluntary testing and consent should be obtained.

4.2 Post-test Counselling

Post-test counselling should ideally be done by the same counsellor who did the pre-test counselling. This should cover negative, positive and indeterminate results.

Post-test counselling in positive cases is done after confirmation by a supplementary test and should be done without delay. During the counselling

process time should be given for the client to understand the meaning of test results, allow ventilation of feelings such as silent, anger, fearfulness, hopeless etc. Emphasis should be given on the difference between HIV infection and AIDS. The counsellor should further explore and acknowledge the various psychological reactions and concerns of the client; what the client plans to do in the short and long term period. Time should be given for the client to clarify concerns and worries about the test. Counselling process should emphasize modification of risk behaviours and lifestyles to prevent further spread of the virus. Follow up should be given in all cases of positive results.

In cases of negative result, assessment of clients understanding of negative result should be done with emphasis on issue related to "window period". If test has been done after 6 months of last exposure, this should be accepted as negative. If the test has been done less than six months from the date of last exposure, the test should be repeated. Strong emphasis should be given towards modification of risky life-styles and behaviours to prevent possible exposure to the virus.

There may be some cases classified as indeterminate result. In these cases, explanation should be given to the clients and test need to be repeated in three months or as advised by the laboratory. As in other cases, emphasis on modification of risk behaviours should be given.

4.3 Counselling of AIDS Patient

Since AIDS is the terminal stage of illness, counselling of such cases should take into consideration the various issues such as chronicity of illness, physical disability, other medical condition with increasing psychosocial problems not only to the patient but also among the family members. Essentially counselling of these cases is very much similar to supporting the "Death and Dying". Issues relevant to be considered would include "unfinished business" between patients and relatives such as guilt, anger, rejection, expectations etc. There may be occasions to discuss the need to draw-up a "will", the last rites, the presence of family members and friends at their bedside and other issues. Counselling of family members of patient and caregivers may need to be considered in some cases.

CHAPTER 5

COUNSELLING IN SPECIAL SITUATIONS

There are situations where counsellors have to deal with in their clients who present with special problems as :

- (a) HIV positive pregnant women*
- (b) HIV positive women desirous to be pregnant*
- (c) HIV positive mother who are breastfeeding*
- (d) HIV positive children and adolescents*

In cases of HIV positive mother, the risk of transmission from mother to child is 20.0 40.0 % and the risk of transmission through breastfeeding is 2.0%. In all these cases, the decision to be pregnant or continue the pregnancy lies with the patient and her husband, who has to be involved in the counselling process. In our Malaysian context, HIV positive mothers should not be breastfeeding.

HIV positive children may have been infected through blood transfusion or mother-to-child. In these cases the counsellor has to deal with feelings of guilt, depression etc. in the parents, anger, hostility in the siblings and other psychological reactions in themselves. The counsellor has to deal with these children as they grow up.

CHAPTER 6

INTEGRATION OF COUNSELLING SERVICES

Counselling services should be an integral part of management and prevention. If HIV infection and AIDS at National, State and Local levels. It should involve relevant government agencies, NGOs, volunteers or groups of volunteers among the community.

There is a need to expand the telephone counselling services at the National, State and Local levels to help strengthen the counselling services provided. This must be managed by a trained counsellor who is knowledgeable in HIV infection and AIDS. From experience, this is mainly to cater for the need to educate members of public. Besides, the counsellor may explore various psychological reactions with a view to offer face-to-face counselling.

There should be an organized training programme for counsellors conducted at various levels by trainers in the counselling of HIV and AIDS. In the curriculum of the Medical School, Nursing School and other training institutions of the Ministry of Health, a component of HIV and AIDS counselling should be included.

GLOSSARY

AIDS

Acquired Immunodeficiency Syndrome. State of immunodeficiency and fall in CD4 cell count with opportunistic infection in HIV infected individual.

HIV

Human Immunodeficiency virus. The virus that causes Acquired Immunodeficiency Syndrome.

HIV / AIDS COUNSELLING

Active communication between a counsellor and client who presents with problems related to HIV or AIDS with a view to assist the client to deal with these problems adequately and appropriately.

HIV / AIDS COUNSELLOR

A counsellor who has been trained in counselling of HIV and AIDS.

CLIENT

An individual presenting with problem/s to a counsellor.

HIV CARRIER

Asymptomatic but infective stage of an individual infected with HIV.

IMMUNE SYSTEM

The body's defence mechanism which fights off infections and certain diseases.

ANTIBODY

Protein produced by a person's immune system in response to an antigenic challenge - usually an infective process. If HIV antibodies are present then the body has been infected by the virus.

IVDUS

Intravenous Drug Abusers who administer the drug intravenously.

ANTIGEN

Substance or organisms or part of organism which can stimulate the production of antibodies.

OPPORTUNISTIC INFECTION

Infection which occurs in an immunocompromised individual. The organism/s that cause the infection are normally harmless to a "normal" individual.

PRETEST COUNSELLING

Counselling given to an individual before HIV test is done.

POST-TEST COUNSELLING

Counselling given to an individual after HIV test has been done.

HIGH RISK BEHAVIOURS AND LIFESTYLES

Behaviours and lifestyles that exposes an individual to HIV infection eg sharing needles, having multiple sexual partners.